



ALERT

**News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.**

April 1996

Positive Voices Issues CD

Positive Voices, a choir made up of persons living with HIV and AIDS, has issued their first CD: "Windows of Hope." The music's primary focus is the theme of "hope, strength, encouragement, and faith."

Positive Voices was founded in August, 1994 by Jackson Myers, as one of the programs of the Music Ministry of the Cathedral of Hope MCC in Dallas, Texas. It got started quite by accident, according to Myers. "Back in the summer of 1994 I approached David McCollough, the Director of Celebration, about putting a group together for a one-time performance of HIV-positive people. Within a few weeks, it became 'let's form a group that will sing on a continual basis.'"

The choir's number one goal is to become obsolete: "AIDS will be cured and we will no longer need to do what we do," says Myers. Their number two goal is to foster hope through their music and their lives as everyone lives with HIV until that time.

Jackson says the message of the choir is, "You don't have to live with the isolation and the depression and the feelings of hopelessness. No one knows what happens with AIDS, but what you do with each day makes a difference in your life and in other people's lives." Asked how it's made a difference in his own life, he answered, "Being around like-minded people really helps. We try to avoid all of the negative thoughts and emotions that we



Positive Voices from Cathedral of Hope MCC, Dallas, Texas

can, as much as possible. We're a support group for each other, in addition to being a musical ensemble. We meet three times a month. We perform four to six times per year. Being the director is a different kind of challenge: we've never had a rehearsal with everyone there. Even at our recording session, everyone wasn't there. So it can get stressful..."

(see Positive Voices, page 2)

UFMCC Co-Sponsors International Memorial May 19

The 13th International AIDS Candlelight Memorial and Mobilization will be observed world wide on Sunday, May 19, 1996. The event, which began in San Francisco in 1983, honors the memory of those who have died of AIDS, demonstrates support for people living with HIV and AIDS, and mobilizes community-based responses to HIV/AIDS. Once again, the memorial is co-sponsored by UFMCC. Many Metropolitan Community Churches continue to be the primary organization responsible for the event in their local community.

(see Memorial, page 4)

Recommended Reading: Reviving The Tribe By Eric Rofes

Many leaders of UFMCC are reading and talking about *Reviving the Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* by Eric Rofes. This book offers a penetrating analysis of the state of the gay male community after 15 years of living with AIDS. Rofes proposes a number of concrete suggestions for the survival of the community in the face of the devastating effects of AIDS.

Reviving the Tribe is available through UFMCC Resource Center, 5300 Santa Monica Blvd. #304, Los Angeles, CA 90029 USA; phone 213/464-5100; fax 213/464-2123.

(see Reviving The Tribe, page 4)

News From The U.S. AIDS National Interfaith Network

Rev. Ken South, Executive Director of the U.S. AIDS National Interfaith Network (ANIN), recent spoke with ALERT about current HIV/AIDS legislative issues in the U.S. Capitol.

1) HIV in the military. ANIN distributed throughout the United States a "sign-on letter" calling for the repeal of the law which orders the discharge of HIV-positive military personnel. Rev. South reports that the letter has had a good response: so far, there are two solid pages of churches and AIDS ministries signing on. He says "This piece of legislation is one of the most egregious and blatant pieces of discrimination ever passed as law. The other side argues that it only affects 1,000 people, but the military is the largest employer in the U.S. If they can do it, why can't AT&T?" As this newsletter goes to print, the U.S. Senate has voted to repeal the provision that would ban persons living with HIV from the military. It still faces a battle in the House of Representatives.

2) Authorization of Ryan White funds is still stalled in committee in the Senate, as part of a bigger Labor bill. Rev. South explains, "The prob-



Rev. Ken South

lem is other stuff in the bill, not the Ryan White funds." All the funding for HRSA (housing) is under the Continuing Resolution, which ends March 15, so we don't know what's going to happen. The prevailing wisdom is they'll just continue the Continuing Resolution until the new year. The President put in an emergency request for \$52 million additional dollars for Ryan White funds to expand treatment access, specifically access to the new protease inhibitors.

Rev. South urges that local church members continue to call and write their senators regarding Ryan White funds. There is a great urgency for these funds to be released. "We've got to get Ryan White re-authorized." At least one MCC-related AIDS Ministry, the MCC of Sacramento, CA, has lost its Ryan White funding, which means an end to their case management services.

Members are also urged to contact their representatives in the House regarding the bill to repeal the section of the arms and defense appropriations bill which would discriminate against military personnel living with HIV.

On the Interfaith front, Rev. South reports that for the first time at the annual International AIDS Conference, this year in Vancouver, BC, Canada, there will be an AIDS Interfaith Service. South believes this will be "a real witness to the conference." ANIN is co-chairing the event, and MCC will be actively involved. This first-time religious presence at the International AIDS Conference will be held on July 10. ♦

Positive Voices

(continued from page 1)

Myars feels he's benefited greatly from the group: "I've learned that God can take a bunch of nelly sick queens and take us far beyond where I thought possible. One of the disturbing things I've learned is that there's still so much fear about coming out. Many people come up to me and say I'd love to sing with that group, but I'm not ready to stand in front of the congregation, let alone the TV cameras, and say that I'm HIV-positive." In January, there were 30 men and one woman in Positive Voices.

"At the end of every rehearsal, we talk about everyone who's not there and why they're not there. We've attended too many memorial services. We've lost six from the group so far. Three of those were in the first three months, and that was quite devastating. We don't deny what's going on, but we turn it over to God at the end of the rehearsal. We're helping God by helping take care of the people within the group who may be sick.

"I think it's possible for other churches to do this. One of the good things about this is it's an alternative to the sanctuary choir, which is so busy and so demanding. Many of the HIV+ people who want to sing but can't keep up with that schedule, are finding a musical outlet within this group."

The compact disc was recorded, at least in part, because they wanted their music to be available far beyond Dallas, and they don't feel it would be feasible for

them to tour the way some groups do.

Nevertheless, the CD is a beautifully produced testament to their hope and faith. The music, some of which is original, is consistently well-performed and inspirational. One track features the Cathedral of Hope Sanctuary Choir and Orchestra performing "God Will Make a Way." Those who attended General Conference XVII in Atlanta will remember the stirring performance of this piece as well as the inspiring testimonies from persons living with HIV contained within the anthem.

Myars states, "It is certain that through AIDS, we have experienced much fear, along with many hardships, challenges, disappointments and discriminations...We are experiencing a healing that comes not in the form of a cure, but in the journey toward hope. And along that journey we are given a strength beyond our comprehension, a calming encouragement and an unwavering faith that we must, in turn, give away."

The CD is available through the UFMCC Resource Center, 5300 Santa Monica Blvd. #304, Los Angeles, CA 90029 USA; phone 213/464-5100; fax 213/464-2123; or through Sources of Hope, 5910 Cedar Springs Road, PO Box 35466, Dallas, TX 75235 USA; phone 214/351-1901 or 1-800/501-HOPE; fax 214/351-6099. ♦

Names Project Quilt Available to Local Churches; Entire Quilt to be Displayed in October

Small portions of the Names Project Quilt are available to local Metropolitan Community Churches and other religious institutions, through the National Interfaith Quilt Display Program.

Displaying the Quilt provides a special opportunity to encourage awareness, education, and spiritual reflection around the issues of HIV and AIDS. A display of the Quilt is a powerful way to motivate your community to show respect and compassion for those affected by AIDS.

The National Interfaith Quilt Display Program allows religious institutions to display small portions of the Quilt for a maximum of 30 days. The fee structure is based on \$200.00 for each 12' by 12' section with the option of displaying up to four 12' by 12's for a maximum of 30 days.

If a Names Project chapter is located near you, contact the chapter. The chapter may be able to support your event locally. If there is no chapter in your area, or it is unable to fulfill your display request, please contact Judy Noddin, Display Coordinator of the National Interfaith Quilt Program for an application and further instructions. She can be reached at The Names Project Foundation, 310 Townsend Street, Suite 310, San Francisco, CA 94107; phone 415/882-5500, fax 415/882-6200. There is a 90 day timeline to process the application.

The entire AIDS Memorial Quilt - an expected 45,000 individual panels - will be unfolded on the Mall in Washington, D.C. during the weekend of October 11-13, 1996. Twice the size of the 1992 Washington, D.C. display, the 1996 showing of the Quilt will demonstrate once again the tremendous human toll AIDS has taken, and will spur people who see it to action aimed at stopping the epidemic. Because of this undertaking, all other display activity will be closed between August 1 and November 22, 1996.

Also because of the October display at the Nation's Capitol, applications for an Interfaith World AIDS Day Display on December 1, 1996, must be submitted no later than August 1, 1996. ♦



POZ Presents Fifty Actions The U.S. President Could Take To Fight AIDS

POZ, the magazine for people impacted by HIV/AIDS, along with a coalition of AIDS organizations, have developed a list of 50 immediate actions President Clinton, or any U.S. President, could take to fight AIDS. The coalition includes the National Association of People with AIDS, Housing Works, PWA Coalition/New York and several ACT UP chapters.

The list covers a wide range of areas where the federal government could act, including health care delivery, housing, research, immigration, education and prevention, and advocacy. By using the powers of veto and executive order, each of these 50 actions could be taken with the stroke of a pen.

"Fifty For The Future" appears in the February/March issue of POZ. Some of the 50 actions the President could take to fight AIDS include:

- * Direct the Centers for Disease Control and Prevention (CDC) to oppose any mandatory HIV testing or AZT use during pregnancy;
- * Direct the Health Care Finance

Administration to mandate Medicaid coverage of HIV counseling and testing;

- * Veto any bill that weakens the budget authority of the National Institutes of Health (NIH) Office of AIDS Research (OAR) or fails to set fixed funding levels;

- * Stop blocking the proposed UCSF clinical trial comparing marijuana to Marinol for HIV-related pain, wasting, and nausea;

- * Order that CDC certify the usefulness of needle-exchange programs

to remove existing restrictions on using federal funds for such programs;

- * Appoint a surgeon general committed to frank AIDS prevention education, needle exchange, and a high profile on AIDS issues.

"During this Presidential primary season, the "Fifty For The Future" will be a handy guide for questioning Presidential candidates about their knowledge and positions on HIV/AIDS," said POZ's editor-in-chief David Drake. ♦

ALERT

ALERT is a quarterly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. Dr. A. Stephen Pieters. For more information, please write: ALERT, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029; or call 213/464-5100; fax 213/464-2123.

Memorial

(continued from page 1)



"Our theme this year is 'AIDS Discrimination Is A Global Epidemic,' Program Director Ben Carlson said. "Around the world, people with HIV and AIDS suffer discrimination caused by fear, ignorance, and misconcep-

Reviving The Tribe

(continued from page 1)

Rofes, a veteran community activist and leader, was a keynote speaker at UFMCC's 1995 General Conference XVII in Atlanta. He will be a consultant to UFMCC AIDS Ministry at a long-range planning meeting in July, 1996.

His twelve recommendations for regenerating community speak directly to the challenges faced by local Metropolitan Community Churches. MCC can take a leadership role in making these recommendations realities. Rofes acknowledges that MCC's and other gay/lesbian spiritual organizations "receive condescending, grudging acceptance by political activists, intellectuals, and service providers." He suggests that "the burgeoning need of gay men to sort things out spiritually should not be suppressed for political ends." (p.273).

The book speaks eloquently on issues for HIV-negative gay men. A number of MCC's are starting programs for those who are HIV-negative, acknowledging the need for support of this part of the community. Rofes' book is a great resource for those interested in these issues.

Rofes' book is a challenging look at the state of the gay male community today. His ideas and recommendations are important considerations for every MCC. ♦

AIDS Ministry Resources on The Internet

UFMCC AIDS Ministry resources are available on the Internet at <<http://www.thebody.com>>. The Body is cyberspace's first one-stop shop for reaching AIDS experts, organizations, and publications.

In addition to UFMCC AIDS Ministry pamphlets on living with HIV/AIDS, The Body features a bi-weekly column on Christian Spirituality and HIV/AIDS, written by Rev. Steve Pieters, Field Director of UFMCC AIDS Ministry and editor of ALERT. ♦

tions about the disease. We believe that policies that reduce the stigma of HIV, and build the self-esteem of people who are at risk for HIV or who have HIV, can create the environment of trust and cooperation necessary to change behavior and reduce HIV transmission. But discriminatory policies promote, rather than prevent, the continuing spread of HIV."

Additional information about HIV/AIDS discrimination is available on the Candlelight program's new site on the World Wide Web: (www.hooked.net/users/candle).

The International AIDS Candlelight Memorial and Mobilization is coordinated under the auspices of Mobilization Against AIDS, a San Francisco-based non-profit organization. MAA supplies event coordination kits to local groups, such as AIDS service organizations and churches, which then coordinate observances of the event. Local observances range in character from small gatherings in houses of worship to huge marches through city centers. In 1995, the event was observed in 250 cities in 47 nations, making it the world's largest annual community-based AIDS event.

Anyone interested in organizing a local observance of the 13th International AIDS Candlelight Memorial and Mobilization may call Mobilization Against AIDS at 415/863-4676, or may register online through the program's Web site. ♦

Conference Announcements

Strictly Positive Wellness Conference

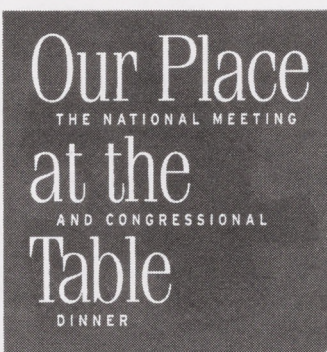
May 18, 1996; Walt Disney World, Florida. The third annual "Strictly Positive" Wellness Conference, free to all HIV/AIDS individuals, infected or affected. Sponsored by the Walt Disney World Dolphin, Walt Disney World Company and other corporations. For more information, write Michael Fuchs, Conference Coordinator, Hope and Help Center of Central Florida, Inc., 1935 Woodcrest Drive, Winter Park, Florida, USA 32792; phone 407/645-2577; fax 407/645-1570.

Our Place At The Table: Advocacy on U.S. Capitol Hill

May 19-21, 1996; Washington, D.C.

AIDSWatch 1996 Advocacy - Capitol Hill on May 21, 1996. For registration form, contact Conference Registrar; 1996 Our Place At The Table; 1931 - 13th Street, NW, Washington, DC 20009 USA; phone 202/483-6622; fax 202/483-1135.

Registration required by May 3, 1996.



(see Conference, page 6)

Medical News

Accessing Crixivan, A New Protease Inhibitor

The U.S. Food and Drug Administration (FDA) approved a new protease inhibitor, Crixivan, the first anti-HIV drug developed by Merck's AIDS research program. Crixivan disables the protease enzyme that enables HIV to replicate. Crixivan can be taken alone or in combination with other anti-HIV drugs such as AZT or 3TC.

Clinical trials have demonstrated that Crixivan treatment results in higher CD4 cell counts and reduced amounts of HIV in the blood. Crixivan is also generally well tolerated. Crixivan will wholesale for \$4,380 per year, or \$12 a day. This is less expensive than the other protease inhibitors, Invirase (saquinavir) and Norvir (ritonavir).

Crixivan is not available in drugstores at this time. Merck is building new production facilities, and must limit the initial distribution of Crixivan to ensure that all those who start Crixivan therapy will be able to continue the therapy uninterrupted. The new facilities will not be

operational until sometime after October of this year.

Until then, Crixivan will be available through Stadtlanders, a mail order service. To get Crixivan, physicians must fax prescriptions and an enrollment form to Stadtlanders at 1-800-238-1549.

To get information about Crixivan, assistance with insurance coverage or patient assistance programs, call Stadtlanders at 1-800-927-8888.

The limited supply of Crixivan will be distributed on a first come, first serve basis. Doctors must contact Stadtlanders, not patients. Patients must speak to their physicians about starting and maintaining Crixivan therapy. Therapy must not be interrupted.

For more information, contact Moises Agosto or Richard Ehara, Research and Treatment Advocacy Department, the National Minority AIDS Council, 1931 - 13th Street, NW, Washington, DC 20009, phone 202/483-6622; fax 202/483-1135. ♦

[The following two articles are reprinted with permission from AIDS Treatment News. "NTZ" was in Issue Number 239, January 19, 1996; "Ritonavir" was in Issue 243; March 15, 1996. To subscribe to ATN, write P.O. Box 411256, San Francisco, CA 94141.]

Ritonavir, Abbott Protease Inhibitor, Approved By U.S. FDA

With record speed, ritonavir (NorvirTM), Abbott Laboratories' protease inhibitor, was approved by the FDA on March 1, 1996 (one day after approval was recommended by the FDA's Antiviral Drugs Advisory Committee) - and was for sale in some pharmacies within a week.

Ritonavir is the only protease inhibitor which already has proven survival benefit (the others might work just as well, since they have comparable effects on viral load and CD4 counts, but they have not completed their clinical-endpoint trials yet, so no data on survival are available). But ritonavir has also raised more safety concerns than the others. It has strong interactions with many drugs used by persons with HIV; it should not be used concurrently with at least 22 of them, and requires dose reduction and/or monitoring with some others. Patients taking other medications must consult with their physicians before starting ritonavir. Abbott has prepared physician and patient instructions regarding potential drug interactions.

Other concerns are that ritonavir has little safety data beyond six months at this time. It strongly inhibits a specific liver enzyme, which presumably is in the body for a reason; blocking this enzyme for extended periods might cause problems. And we have heard more anecdotal reports of side effects with ritonavir than with the other protease inhibitors.

There is also the problem of resistance and cross resistance (especially cross resistance to Merck's Crixivan); this may be minimized by optimal use of the drug - by combining it with two or more other antivirals, and by not missing doses or taking "drug holidays."

(see Ritonavir, page 6)

NTZ: Cryptosporidiosis New Treatment

By John S. James

A new drug which may be the best cryptosporidiosis treatment yet is now in small clinical trials. And a compassionate-access program has been announced by developer UNIMED Pharmaceuticals, Inc.

We first heard about NTZ (nitazoxanide) from a physician we know, who believes he acquired the parasite when public water supplies in the San Francisco area were heavily contaminated last winter. He received the drug by volunteering for a small trial in Mexico City. At first it did not work; he had to increase the usual starting dose (500 mg twice a day). Now the cryptosporidiosis, which had been serious enough to require TPN for several months, is largely controlled although not cured; stool tests are usually negative, but occasionally some diarrhea returns and stools become positive again. Although a course of treatment often lasts only 14 days, he has been on the drug for several months.

All 14 of the people in the Mexico City trial had their stools become negative for cryptosporidiosis. We do not know how many of them have continued with maintenance treatment.

NTZ can cause side effects of nausea and vomiting, so it is usually taken with a small amount of food. NTZ appears to be effective against many intestinal parasites; over 1,000 people have taken the drug so far, almost all outside the U.S. UNIMED recently started a phase III trial for persons with AIDS in Mexico.

In the U.S., a small study is now recruiting at Cornell Medical Center in New York City, and possibly at a second site in San Francisco. Those enrolled will be ran-

(see Cryptosporidiosis, page 6)

Ritonavir

(continued from page 5)

It is likely that many people who could afford to wait a few months or more before starting protease inhibitors may choose to do so. By that time, the Merck drug will also be available; and physicians will know more about which drugs to choose and how to make best use of them. Combinations may work best when a patient starts all the drugs in the combination at about the same time, without extensive prior use of any of them.

Ritonavir is the most expensive antiviral; Abbott's charge to wholesalers is \$6500 per year. We found some confusion about retail prices; patients should check several pharmacies, including mail-order or other large pharmacies serving many persons with HIV, before making major purchasing decisions.

Because interrupting therapy can make one more likely to develop virus resistance to this and some other protease inhibitors, persons should avoid starting either ritonavir or indinavir unless they expect to be able to continue without interruptions.

For assistance in getting reimbursement for ritonavir, call 1-800/659-9050. ♦

Conferences

(continued from page 4)

Annual Conference For Pastoral Care and HIV/AIDS

May 29 - June 3, 1996, Merrimack College, North Andover, MA. Conference title: "From Cover to Cover: A Celebration of Story." For more information and registration, contact the Center for Ministries, Merrimack College, North Andover, MA 31845; phone 508/837-5337.

AIDS, Medicine and Miracles Conferences

April 12-14:	Denver, CO
May 30 - June 2:	Rhinebeck, NY
July:	Vancouver, BC
October 10:	Washington, DC
November:	Houston, TX

For more information, contact the AM&M office at P.O. Box 9130, Maxwell Building, 311 Mapleton, Boulder, CO 80301-9130; phone 303/447-8777; fax 303/447-3902; Toll free 1-800/875-8770.

XI International Conference on AIDS

July 7-12, 1996; Vancouver, British Columbia, Canada. To register, contact the Conference Secretariat, P.O. Box 48740, 595 Burrard Street, Vancouver, British Columbia, Canada, V7X 1T8, phone (Canada/US): 1-800/780-AIDS; Worldwide phone: 604/878-9995; fax 604/668-3242; e-mail: <aids96@hivnet.ubs.ca>. World Wide Web site: <<http://unixg.ubc.ca:780/-aids11/aids96.html>>.

U.S. National Lesbian & Gay Health Conference and AIDS/HIV Forum

July 13-17, 1996; the Westin Hotel, Seattle, WA. To register, contact NLGHA '96 Conference, P.O. Box 33022, Washington, DC 20033, fax 202/659-5559.

Cryptosporidiosis

(continued from page 5)

domly assigned to 14 days of treatment with 500, 1000, 1500, or 2000 mg per day, with 14 and 28 days additional courses of treatment available for those who do not have a complete response.

Also, a compassionate access program has been announced for those who cannot participate in the controlled study, due to eligibility restrictions or geography. But this program has only 30 slots, and is almost completely enrolled. It is open for persons ages 3-65, with exclusions for current infection with a number of other intestinal parasites, history of intestinal MAC or intestinal KS, concomitant use of other drugs to treat cryptosporidiosis or microsporidiosis, and some other exclusions.

We do not know of any other way to get NTZ at this time.

For more information about the trial or the compassionate access program, call Sandy Faulkner, R.N., 1-800/864-6330, 8-5 Central Time.

Comment: The number of slots in the expanded-access program is clearly inadequate, and certain to become an issue unless it is increased.

We have heard that the cost of producing NTZ is very low. The cost of administering a large expanded-access program could be significant. But the FDA has regulations to allow companies to charge to recover this cost. The developer could be reimbursed for any costs, and hire a contractor if necessary to administer the program.

If the program is limited because of safety concerns about a new drug, then the FDA should re-examine the risks vs. benefits. Many people die from cryptosporidiosis and there is no approved or satisfactory treatment. The fact that all 14 participants in an early trial became negative in stool tests implies that NTZ can at least control the disease for some period of time in a great majority of cases. A thousand people have used this drug; unless there is some major safety concern we do not know about, the risks of a larger program are clearly worth taking.

[Editor's note: A trial of NTZ will take place in Australia. The trial will be administered by John Bacon, the General Manager of Therapeutics at "MDA Pharma," a division of Medical Dynamics Australia. He is located in Mona Vale, NSW, and his phone number is 02-9997-7677. His fax number is 02-9997-1233.] ♦

Conferences (cont'd)

U.S. National Skills Building Conference

October 10-13, 1996, Washington, DC. For information and registration, contact: 1996 National Skills Building Conference, 1931 - 13th Street, NW, Washington, DC 20009-4432; phone 202/483-1124. ♦